Bindy Sweett Honored as 2010 Mary Barkey Clinical Excellence Awardee

The Child Life Council established the Mary Barkey Clinical Excellence Award in 2009 to recognize child life specialists who have demonstrated exemplary child life care and a high level of clinical skill. The inaugural award was presented to Bindy Sweett, CCLS, at the 28th Annual Conference on Professional Issues in Phoenix, Arizona.

What is clinical excellence? The Webster Dictionary defines excellence as the “state of possessing good qualities in an eminent degree; exalted merit; superiority in virtue” (www.webster-dictionary.net). The ten criteria developed for the award were designed to focus on key tenets of providing clinical excellence and quality psychosocial care. Two endorsement forms were required as part of the nomination process from CLC members. Although the names of the individuals remain confidential, with their approval, we are pleased to share some of their words as to why Bindy Sweett exemplifies clinical excellence.

A. Demonstrates the ability to work collaboratively with other health care team disciplines in the delivery of patient care which results in positive outcomes for patients

Bindy has worked with numerous teams including Cardiology, Pain Service, Surgical Day Care, and Pre-Admission. Bindy was instrumental in establishing child life services in Surgical Day Care and has made child life services integral to the care patients and families receive before surgery and procedures. In addition, Bindy has worked for many years with the Children’s Heart Network. Within the cardiac team, Bindy has worked extensively at integrating child life – she is a valued healthcare professional and team member.

The Child Life Alphabet

IS FOR

Healthcare Educators:
Promoting Opportunities for Effective Learning

Mary Cataletto, MD, Claudia Fernandez, MD, Nicole Almeida, MS, CCLS, Winthrop University Hospital, Mineola, NY

We all know that repetition facilitates the retention of factual information and that the same information presented in different ways increases the likelihood that it will be understood. This is particularly important for children who have repeated emergency department visits or extended hospital stays. Using asthma as an example, the National Institutes of Health (NIH) recommends that we take every opportunity to educate asthmatic children about their disease, its triggers, and their individual action plan in an effort to minimize acute care visits and hospitalizations.

With grant funding from the Asthma Coalition of Long Island, a multidisciplinary team composed of members of the pediatric staff of Winthrop University Hospital embarked upon a collaborative project which provided children in emergency and hospital settings with a tailored educational intervention. Child life specialists were trained in asthma fundamentals and given interactive tools to work with medically stable children in the emergency department (ED) and

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The Year in Review
Ellen Good, MS Ed, CCLS
Yale-New Haven Children’s Hospital, New Haven, CT

As I reflect upon the previous year, I am amazed by and proud of all of the work undertaken and accomplishments achieved by the CLC Board of Directors, committees, special task forces, CLC Executive Director Dennis Reynolds, and the Child Life Council staff.

It has been a privilege and a pleasure to have worked with such a talented and dedicated group of professionals, each committed to effecting positive change for our membership.

At this juncture, we find ourselves a strong and fiscally viable membership organization; an organization which has implemented many new and exciting initiatives. Some of these include:

- The Mary Barkey Clinical Excellence Award was established and presented at the CLC Annual Conference in Phoenix to Bindy Sweett, CCLS.
- Worldwide Outreach Scholarships, were awarded to allow four individuals from around the world to travel to Phoenix and attend the Annual Conference.
- Three task forces were established as a result of recommendations coming out of the 2009 Academic Summit. These include the Internship Task Force, Academic Task Force, and the Research and Scholarship Task Force.
- The Patient Ratio Task Force was an additional task force formed to review the current recommended child life specialist-to-patient ratio, identify a reliable measure for a needs assessment, and determine what type of data collection tool is needed.
- CLC’s online systems and outreach were expanded to include opportunities for enhanced professional networking and resource sharing via CLC Community, educational webinars, an improved member directory, CLC pages on Facebook, Twitter, LinkedIn, and more.

In closing, I would like to once again thank many individuals for their kind support during my year as President. It has been both an exhilarating and humbling experience to lead this organization through such an exciting time of progress. As I hand over the gavel to incoming President Eugene Johnson, MA, CCLS, I look forward joining all of you in promoting CLC’s continued growth and success.

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For information on how to place an ad in the Bulletin, please refer to the Marketing Opportunities section of the CLC Web site: http://www.childlife.org/Marketing Opportunities/

Research Review
Parental Presence for Anesthesia Induction: Is It Best Practice?


Lindsay Heering, MS, CCLS, CTRS, Children’s Hospital of Michigan, Detroit, Michigan

Having surgery, particularly anesthesia induction, can be anxiety-provoking for children. Child life specialists routinely advocate for parental presence as a strategy to increase positive coping, reduce anxiety, and enhance compliance. Should they? Is parental presence best practice? Despite the belief that it is, a recent systematic review failed to find support for parental presence as an intervention to alleviate anxiety.

This systematic review included studies which examined the effectiveness of parental presence as compared to other interventions or standard care. Studies measuring anxiety post-discharge were excluded. The studies were found by searching MEDLINE (1950-2008) and EMBASE (1980-2008). Only studies that were rated at evidence levels I-III were included, for a final group of fourteen studies, published between 1988 and 2006. None of these studies were rated as level I evidence. These studies assessed parent and child anxiety using physiological, observational, and self report measurements at varying times during the surgery process.

In studies that focused on parent anxiety, the authors found no significant differences between parents who were and were not present for induction. Only one significant difference appeared in a study where parents’ diastolic blood pressure and pulse rates were lower for the non-presence group.

Children’s anxiety was examined in another selection of studies. The majority found no significant differences between

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Changes for Bulletin
Anne Luebering Mohl, PhD, CCLS, Johns Hopkins Children’s Center, Baltimore, MD

It seems that we’re always hearing about change. It’s coming at us from every direction; from manufacturers touting new and improved products, from politicians advocating for new policies, and from corporations striving to survive in a changing economy.

I would like to highlight a few changes you’ll be noticing in Bulletin and Focus over the next few issues. You’ve probably already picked up on the most obvious change: a new color scheme. The editorial team thought this might be an opportune time to change things up a bit and give the publication a slightly fresher look.

Another immediate change is more subtle: there has been a transition in the editorial team. Joan Turner, who has done an amazing job in her service as Executive Editor for two years, is rolling off of the editorial team and has taken on a new role as Chair of the Research and Scholarship Task Force, although she will continue to contribute to Focus as a member of the Focus Review Board. I have stepped in as Executive Editor, and Jaime Bruce Holliman is taking over as Associate Editor. In addition, we’d like to thank Estelle Argie-Hawley, Jane Darch, Suzanne Graca, Diane Hart, and Eileen Mapes for their service as they finish their terms on the Focus Review Board.

Probably the most exciting changes in Bulletin come in conjunction with the introduction of CLC Community. As we come to rely on this new way for CLC members to connect individually and as a group, you will see such new tools as a Bulletin blog, opportunities to comment on and discuss Bulletin/Focus content, and links to resources for those interested in exploring further after an article piques their interest. We expect that the connection between our print publications and CLC Community will evolve as we all discover the most useful ways of using CLC Community.

One change that we want to encourage is the way that each of you as CLC members thinks of yourself as a potential contributor to Bulletin/Focus. The editorial team knows that child life specialists are innovative people with exciting ideas, research interests, and programming successes to share. Although in our jobs, we are accustomed to lowering our inhibitions and putting ourselves “out there” when working with children—singing songs, acting goofy, discussing sensitive subjects without cringing—we are often a bit more hesitant to let our guards down when our intended audience is our peers, the community of child life specialists. We know that we all benefit greatly from what we learn from each other, so we would like to encourage and assist potential authors in any way we can. Browse the Bulletin/Focus section of the website; there are useful tools to guide you through the writing and submission process. Contact a member of the editorial team; our names are in each issue. If you feel that you have something important to share but are concerned that your writing skills are not up to par, consider asking a colleague or a friend to serve as a writing coach. Someone you know who writes well may be more than happy to help you develop your skills in that area. Finally, as you are preparing your manuscript, pick up a copy of the new version of the Publication Manual of the American Psychological Association (often called the APA Style Guide). A new sixth edition was published this year. The CLC is not the only organization undergoing change!

One final change that I’d like to mention is that we will be introducing a new column that will serve as an overview of the content of each issue of Bulletin/Focus. Some other columns or content that you have seen in Bulletin over the years may eventually shift to CLC Community as it becomes a key communication tool for our organization. As these changes take place, this new column will serve as a bit of continuity from issue to issue.

Change can be a bit unsettling, but it can also be a time of growth. Knowing that the changes that Bulletin/Focus will undergo have been planned thoughtfully and are designed to move us in a positive direction is very exciting. If you have other ideas for improvement, please contact me. I look forward to serving as your Executive Editor.
A Publication of the Child Life Council

BULLETIN SUMMER 2010

CLC Recognizes Leaders in Philanthropic Support at 28th Annual Conference

CLC awarded the Spirit of Giving award to two recipients this year at the Annual Conference in Phoenix, Arizona.

Starlight Children’s Foundation and Charles D. Rumbarger, CAE, have been selected as the 2010 recipients of the Child Life Council Spirit of Giving Award. The Spirit of Giving award, established in 2007, is designed to recognize organizations and individuals making significant monetary or in-kind contributions that have a positive impact on child life programs on a national or international level.

For more than 25 years, Starlight Children’s Foundation has helped seriously ill children and their families cope with their pain, fear, and isolation through entertainment, education, and family activities. In fulfilling this mission, Starlight brings together experts from pediatric healthcare, technology, and entertainment to create programs that educate, entertain, and inspire seriously ill children. In providing Starlight programming, the child life specialist is equipped with invaluable resources to help children and families cope with the challenges they face daily.

Charles D. Rumbarger, CAE, is one of the association community’s most experienced and acknowledged professionals. Currently President of Organization Guidance Group, LLC, his professional path has spanned almost forty years. In 2008, the Child Life Council initiated a Governance Task Force to review best governance practices in associations and board development. Mr. Rumbarger served as a pro-bono consultant offering CLC expert leadership, invaluable knowledge, significant time, and resources. During CLC’s Executive Director Search in 2009, Mr. Rumbarger provided a smooth transition of leadership, setting the stage for ongoing growth and development of the organization and the profession.

Role of Child Life During the H1N1 Epidemic

Renée Ethans, CCLS, Children’s Hospital, Health Sciences Centre, Winnipeg Regional Health Authority, Winnipeg, Canada

The H1N1 influenza strain swept into our lives in Spring 2009, taking everyone by surprise. By June 11, the World Health Organization declared it a Level 6 Pandemic. Healthcare providers quickly responded, and by the second phase in Fall 2009, there was an unprecedented readiness in terms of worldwide immunization programs. Best practices were in a state of flux, evolving to stay in step with knowledge about the disease and dealing with the escalating numbers of the affected. By March 7, 2010, more than 213 countries and overseas territories or communities had reported laboratory confirmed cases of pandemic influenza H1N1 2009, including at least 16,713 deaths (http://www.who.int/csr/don/2010_03_12/en/index.html). Child life was one discipline that responded and adapted to the growing demands of H1N1.

Our Experience in Winnipeg

Winnipeg was the North American epicenter during phase one of the H1N1 pandemic, which provided us with unique experience and insight to share with facilities around the world. As the only tertiary care hospital serving all of Manitoba, Northwestern Ontario and Nunavut, Health Sciences Centre Winnipeg was hit hard in Spring 2009.

There were 892 reported cases of H1N1 in the first wave; the second saw 1,774 reported cases in Manitoba (population 1,148,401). Canada aimed to immunize every citizen. Over 250,000 people in Winnipeg were vaccinated, out of a population of 694,668. However, the disease spread especially rapidly in our remote Northern communities. Visits to the Children’s Emergency Department more than doubled, with four times more patients than usual with influenza-like symptoms. Families were understandably anxious. Child life specialists were quickly called upon to make adaptations in their programs that would protect the patients, staff, and public and make them feel safe when coming into the hospital.

The Winnipeg Regional Health Authority issued daily or weekly communications with updates regarding the numbers and spread of the disease and changes in protocols, including complex consultation with Infection Prevention and Control Practitioners regarding cohorting and clustering patients with flu-like illness, increased use of personal protective equipment and hand sanitizers, restrictions on the numbers of visitors, removal of shared items in waiting rooms, increased hand wash stations, increased signage regarding hand washing and cough etiquette, immunization clinics, and information about symptoms and what staff should do if they had symptoms. Under these missives, the Child Life Department worked with the Child Health leadership team and Infection Prevention and Control to assess and adapt our practices.

Child Life Specialists Respond to the Outbreak

During the first outbreak, child life spe-

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Wide eyes stared at Samuel* and took in every detail of his newly changed appearance. The fifth grade class seemed very hesitant to speak at first, and no one was willing to break the nervous silence. Our patient lingered behind the social worker and me, unwilling to face his classmates. He watched and waited while I spoke to the classroom full of his peers, teachers, and counselors. As I finished answering each child’s question, ranging from relevant topics to slightly more digressive themes, I saw a small smile on our patient’s face. He finally cracked a grin over a particularly interesting question regarding the possibilities of healing a pet dog’s leg with an external fixator. After this question, Samuel felt comfortable approaching his classmates, showing them the Taylor Frame fixator on his leg, and pointing out his skin grafts. Imagine the same classroom scenario if that patient had not received the benefits of a school reentry program. Would he have had the tools and knowledge to face his classmates, or would he have shut down and withdrawn from the confused looks and questions of his peers?

Months earlier, as the result of a car accident, this patient suffered a brain injury, along with damage to his leg that required numerous surgical skin grafts and an external fixator. He had been an inpatient in our Neurological Rehabilitation (Neuro Rehab) program for three months and would be returning to school a few weeks following his discharge. To ease his transition back to school, our Neuro Rehab team created a successful school reentry presentation, delivered it with the patient at his school, and allowed him to have support for such a challenging situation.

Experiencing this moment of true interdisciplinary collaboration opened my eyes to the importance of providing school reentry resources for my patients. The patients in the Neuro Rehab population that I work with have a wide variety of diagnoses that include traumatic brain injury, brain tumor, Guillain-Barre Syndrome, epilepsy, and others. Often, these patients are hospitalized for a lengthy period of time, ranging from three weeks to several months. The patients on the Neuro Rehab service face a wide range of new challenges before, during, and after their hospitalization. One particular, often overlooked challenge for these patients is the transition back into the school environment.

Research shows that “the number of children who return to school with chronic illnesses has increased during the past decade” (Kliebenstein & Broome, p. 579). School staff members do not feel adequately prepared to welcome patients back into the classroom because they do not have specific training regarding the patients’ diagnoses or the changes they have experienced during their time in the hospital. Kliebenstein & Broome state that little information is known about the impact of a hospitalized child’s return to school on school personnel. Even less information exists to pinpoint parental issues regarding return to school for these hospitalized children (Kliebenstein & Broome).

A study was conducted to label the issues and needs of school employees as well as parents of children with chronic illnesses during their transition back to school. Focus questions were given to participants of the study and included: the child’s school reentry timeframe, training for school employees regarding the patient’s care, positive features of the reentry process, components of the process that require improvement, and suggestions to provide an easier and less stressful school transition (Kliebenstein & Broome). Results showed that parents experienced several concerns regarding their child’s school reentry process, including a lack of attention to their child’s new and specific needs throughout the school day. An overwhelmingly prevalent concern for parents of hospitalized children was the lack of communication between their child’s school and hospital (Kliebenstein & Broome). This parental concern makes it critical for us as child life specialists to embrace our role as patient and family advocates and facilitate school reentry opportunities for our patients.

One goal of the Neuro Rehab program at St. Louis Children’s Hospital is to create a school reentry presentation for every school-age patient who completes our program. Collaboration among members of the Neuro Rehab team is the key to creating a successful school transition for our patients. I work closely with our hospital’s school teacher and...
Child Life During H1N1

Continued from page 4

cialists continued providing psychosocial services on inpatient units. Staff followed infection control protocols and continued to see patients to offer preparation, teaching, support, and diversion. Our biggest change was to suspend group activities, so we closed our main playroom to groups. Fortunately, we were able to open it up to patients on a one-on-one basis, to allow them a chance from their wards. Priority was given to long-term, chronic patients, who each could spend at least an hour in the playroom. However, changes to protocol were required in order to provide this level of care.

Because the playroom is either locked when not in use, or supervised when open, the playroom space and materials are monitored consistently. Playroom staff takes great pride in the toy- and space-cleaning policies that have been developed and revised over many years. During the outbreak, the following protocol was followed: before entry, we screened patients for healthiness, showed them cough and sneeze etiquette (i.e. into the elbow) and asked them to use the hand sanitizer. The playroom was only closed for a short period during the first outbreak, and by following these new protocols we did not close it at all during the Fall 2009 outbreak.

ADAPTATION OF CHILD LIFE PRACTICES

There are a variety of actions that child life departments can undertake during an epidemic, and indeed, we have now incorporated them as standard practice. News about H1N1 was at the media forefront and the reports concentrated on ways to prevent transmission. People were scared, and people cared. Families were very respectful and understanding about the introduction of the use of hand sanitizer, visitor restrictions, and the removal of shared items. In fact, we found that families were extremely cooperative and grateful for the measures taken by the hospital during the outbreaks.

Families were very respectful and understanding about the introduction of the use of hand sanitizer, visitor restrictions, and the removal of shared items. In fact, we found that families were extremely cooperative and grateful for the measures taken by the hospital during the outbreaks.

Child life specialists are assigned to inpatient wards that have unsupervised playrooms. Toys were culled and removed from these rooms. We recommended placing toys/games in locked cupboards, leaving out only a few items at a time, and rotating the choices. We also kept toys available for patients to borrow from the ward playroom for isolation rooms. These toys were then cleaned before being returned to circulation. In addition to single-use toys, giveaway items such as colouring books, sudoku books, decks of cards, games, and toys were offered to patients to keep. Unit staff felt relieved when these changes occurred, because they increased the organization of toy inventory and eased the burden of cleaning.

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TOYS FROM HOME

Child life departments have always encouraged families to bring a few personal toys/comfort items from home for their child to play with when they come to the hospital. Even so, many people have come to expect toys in waiting rooms and may not bring anything to appointments. We recommended that this suggestion should be made when appointments were being made so that the family was prepared to bring their own diversions. It was explained that this measure was being taken to protect children from the possibility of infection from shared items. In fact, in our PreAdmission Clinic/Day Surgery, staff even encouraged families to clean their stuffed animal before bringing it to hospital; families understood and appreciated our attention to the health of their children. We also encouraged families of inpatients to retrieve their child’s personal items from home for variety. The giveaway items we have on hand were used as supplements, or for children who came with nothing to play with.

HAND WASH STATIONS

One of the new practices we introduced was to install hand wash stations outside of our playroom, closed-circuit TV station (CHTV) studio, and Book Corner Library/Schoolroom. We placed a sign asking everyone who entered to please use the hand cleaner. Although we have always practiced strong infection control in our playroom, we can always improve, and this ensured that everyone who entered was starting out with clean hands. This, in addition to screening for healthiness and teaching coughing/sneezing etiquette, has continued as standard practice.

ALTERNATE DIVERSIONS

With the removal of toys from waiting rooms, we recommended placing a television and DVD player in a quiet corner of each waiting room to entertain children. We introduced a storyline program in our Children’s Emergency Department waiting room and Children’s Clinic (outpatient) waiting rooms. Our librarians trained and oriented volunteers who rotated through these areas. This is a “cleaner” alternative to shared books and magazines in waiting areas.

OTHER MODIFICATIONS

Our child life department is also home to a daily an interactive live show on CHTV, music therapy, clowning, a library for children and teens, and a resource library for families, students, and staff. Practices were modified in each of these areas to reduce the transmission of infection. For example, the therapeutic clown suspended group activities;
ABSTRACT

Summer camp has a positive impact on adolescents with serious illnesses; in fact, research shows that camp increases hopeful attitudes by decreasing levels of anxiety related to illness (Briery & Rabian, 1999; Turuk, Kukunyeyi, Karolyi, Ittzes, & Tomcsanyi, 2006). Yet, the hopefulness derived from the experience may dissipate when the camper returns to the chronic stress of his/her illness (Hinds, 1988).

This paper reports on a pilot study done in collaboration with Camp For All, a camp for children with serious illnesses. The Zora 3D virtual world was used to create a virtual space resembling the camp facility. The goal was for campers to maintain friendships from camp and explore how to sustain hope and community. The technological intervention called Zora Camp4All was introduced to 40 adolescents with cancer (n=16) and blood disorders (n=6) and their siblings (n=18) during their week at Camp For All in June 2009. After that week, they accessed the network through home or hospital computers and joined one another in the virtual Zora Camp4All.

Since research indicates that camp enhances hopefulness, this pilot research’s main goal was to discover if Zora Camp4All could sustain the campers’ hopefulness after their week of camp was complete. The results from this study suggest that Zora Camp4All might contribute to sustaining hopefulness within the campers; however, significant differences were found in the different populations that participated in the camp experience.

Zora Camp4All: A VIRTUAL COMMUNITY TO AUGMENT THE HOPEFULNESS OF PEDIATRIC CAMPING

Kathryn A. Cantrell, MA & Marina U. Bers, PhD
The Developmental Technologies Research Group, Eliot-Pearson Department of Child Development, Tufts University, Medford, MA

In past research, camping interventions for youth with cancer and blood disorders have been shown to increase the youths’ sense of hopefulness (Hinds, 2004). But what happens when the youth return home to their routines of doctor’s appointments and medical testing? Unfortunately, little literature addresses the re-entry phase of the camp experience; Hinds (1988) found that hopefulness scores decreased two weeks after programs’ completion, indicating that the positive, goal-oriented attitude evaporated as adolescents assimilated back into their normal routine of chronic stressors.

The intervention described in this paper uses virtual technology to create opportunities for youth to maintain their sense of hope after the end of camp. The Zora multi-user virtual world platform, developed by Marina Bers and her research team at Tufts University, was utilized to create a specific virtual space mirroring Camp For All, a pediatric camping facility located in Burton, Texas, that caters to both ill children and their healthy siblings (Bers et al., 2010; Bers, 2009). First introduced to adolescent campers (aged 13-17) with cancer (n=16), blood disorders (n=6), and their siblings (n=18) during their week at camp in July of 2009, the virtual world allowed users to chat with their friends from camp, share memories, and construct virtual spaces and objects about their week. Upon returning home, the secure software became accessible 24/7 and provided facilitated group activities to promote hopefulness in the spirit of Camp For All. The virtual world, named Zora Camp4All, remained open for three months until October 1, 2009.

The construct of hope is valued for enhancing quality of life for individuals experiencing an illness (Herth, 2001; Hinds, 2004). Being hopeful is a significant determinant of psychosocial adaptation among adolescents with a chronic illness; likewise, the outcomes of hopefulness among these adolescents are a commitment to treatment, adaptation to symptoms, and taking care of problems (Hinds & Martin, 1988). Hinds (1988) found that the hopefulness of adolescents with a substance abuse history decreased once reentering the context they left. The same might be said for many adolescents who find hopefulness while at camp and then return to hospitals, IV poles, and lab coats.

Technological interventions, specifically virtual worlds, have been shown to benefit an individual’s need for community (Donath, 1996; Bers et al., 2010). Erikson (1982) explains that the adolescent’s stage of development, identity versus role confusion, makes social interaction and connections vital for exploring one’s identity and adult roles. For adolescents with an illness in the family, opportunities for social inclusion are often interrupted by disease-related activities such as hospitalizations or treatments (Snyder, 2000). The inclusion of a virtual world within camp programming, in particular as a way to sustain the camp experience after it physically ends, is an additional vehicle for campers to maintain their social connections as it provides community when the adolescent is unable to attend camp or is isolated within the hospital.

This pilot research had multiple goals including determining if the hope-based, camp-inspired tool of Zora Camp4All could 1) sustain the campers’ sense of hopefulness after their week of camp, 2) sustain the...
The concept of hope is central to Camp For All’s culture; ubiquitous in the language of the staff, it even appears within the camp’s ambitious motto, Love, Laughter, Hope, and Healing. The construct of hopefulness has morphed from the initial definition of “a desire to seek goals” to the now multi-faceted positive psychology theory that defines hope for adolescents as “the degree to which an adolescent possesses a comforting or life-sustaining, reality-based belief that a positive future exists for self and others” (Korner, 1970, p. 134; Hinds, 2004).

Hopefulness places an individual at an advantage when faced with a situation that requires coping. The stress and coping paradigm has guided considerable health-related research for the past two decades, and during this time, hope has been cited as an important variable within the paradigm. Lazarus and Folkman (1984) claim that hope can act as both an emotion-focused and problem-solving coping strategy and as a method of cognitive appraisal. In Snyder and Lopez’s (2003) definition of hope, hopefulness requires action-based thoughts and behaviors leading to a goal, actions that mirror the problem-focused coping strategies such as defining a problem, identifying alternatives, comparing alternatives, and selecting an alternative.

Hope is consistently cited as an essential psychosocial resource for adolescents who are coping with a critical illness and the treatments that accompany the experience; additionally, coping strategies that employ hope are often cited as beneficial for the teen (Herth, 2001; Hinds, 2004; Hinds & Martin, 1988; Ritchie, 2001). In addition, it has been shown that “people who have good medical information and who demonstrate a hopeful, active coping style are likely to deal more effectively when faced with an actual illness experience” (Taylor, 2000, p. 361). According to Taylor, “The hope for recovery and return to one’s healthy life are implicit in the cancer patient’s fighting spirit” (p.363).

Hinds has pioneered the study of hope in adolescents. Hinds’ (1988) quantitative investigation of hope as experienced in a group environment was a longitudinal study of adolescents during treatment in a substance abuse program. During the program, researchers measured hope three times using the Hopefulness Scale for Adolescents (HSA; Hinds, 1988): upon admission (Time 1), prior to leaving the program (Time 2), and approximately a month after discharge (Time 3). Hopefulness scores were much higher during Time 2 than Time 1. Unfortunately, after discharge and once back into their previous context, the adolescent’s hopefulness dropped again one month later. Thus, the findings raise questions about the ability to create a lasting impact on adolescents once the examined program is complete.

In a more recent study, Ritchie (2001) looked at the psychosocial functioning of adolescents with cancer and examined the variations in hopefulness amongst gender and age. The study, which included 45 adolescents with cancer, examined the relationships among stages of adolescence, gender, self-esteem and hopefulness. The greatest determinant for hopefulness was not age or gender, but instead self-esteem. This is important for the psychosocial therapy of an adolescent with cancer as it reminds the facilitator to reinforce not only hope, but self-esteem as well.

While Richie (2001) informs the hopefulness experience for adolescents with cancer, it does not answer whether this experience is universal for siblings and adolescents with blood disorders. For example, while the patient is able to draw hope from a healthcare team that works to maintain a positive attitude, the sibling might not have the same resources. Cantrell and Lupinacci (2004) found that individuals without an illness experienced lower mean scores of hopefulness when measured with the Hinds’ Hopefulness Scale for Adolescents (HSA) compared to individuals with an illness.

Additionally, adolescent siblings of individuals with an illness are at increased risk for internalizing disorders including depression, anxiety, and obsessive-compulsive symptoms (Stawski, Auerbach, Barasch, Lerner, & Zimin, 1997). Unfortunately, far less research on hopefulness has been conducted on family members of those individuals with a serious illness. Lanin-Kettering (2009), though, demonstrated that the social support program, SuperSibs!, increased the siblings’ sense of hopefulness; in fact, 75% of siblings noted that they felt stronger and more hopeful after receiving SuperSibs! services.

Qualitative studies across the age and health-illness continuaus have identified potential hope-fostering strategies and interventions and have laid the groundwork for future intervention studies in clinical populations (Herth, 1990, 1993a, 1995b, Koopmeiners et al., 1997). Specifically, interventions employing hope as their theoretical backbone have been introduced to adult populations experiencing cancer (Ferran, Wilken, & Popovich, 1992, Herth (2001). Herth employed the Hope Intervention Program (HIP) in a study with 38 adults with first recurrence of cancer. Data suggested that HIP positively affected the participants’ rebuilding
and maintenance of hope. Additionally, 92% of the participants “felt that having an opportunity to meet and share with group members, feeling support of others, and realizing that they shared many similar thoughts and feelings was extremely helpful” (Herth, 2001, p. 1016).

Cantrell and Conte (2008) chronicled the outcome of an online intervention aimed at enhancing hope in adolescent female cancer patients. The eight-week program also employed Herth’s (2001) Hope Intervention Program curriculum. The six participants and the researchers met online as a group once a week for 2 hours each session. Participants felt that, “of all the HIP sessions, [. . .] those sessions in which they shared their thoughts and objects of hope with the other participants” were most beneficial (Cantrell & Conte, p. 376). Participants mentioned that just the ability to share their stories promoted a feeling of trust and hopefulness within the group, and months later, participants still considered the group to be a valuable addition to their lives.

While interventions employing hope have been introduced to adolescents diagnosed with cancer, the same cannot be said for adolescents with sickle cell disease, hemophilia, or siblings of adolescents with chronic illnesses. This project, though, extends the sample to include campers with blood disorders (n=6) and campers who are siblings of individuals with a chronic illness (n=18). The combination of these populations within the sample provides an understanding of how interventions like Herth’s (2001) HIP can be employed in other arenas.

**CONTEXT OF THE INTERVENTION**

The intervention, Zora Camp4All, utilizes a virtual community developed using the Zora platform created for the campers at Camp For All in Burton, Texas (Bers, Gonzalez-Heydrich, & DeMaso, 2001; Bers, Chau, Satoh, & Beals, 2007; Bers, 2009). The program was introduced to the campers while they were attending their week-long session at the physical camp, Camp For All. This article examines the effects that both the camp and the technological intervention, Zora Camp4All, had on the campers; thus, it is important to understand the two contexts of the intervention: the physical Camp For All and the virtual Zora Camp4All.

**Camp For All**

The adolescent experiencing a serious illness, either in themselves or within the family, is at a greater risk for experiencing higher levels of hopelessness and psychosocial concerns, including behavior problems, poor self-concept, and social withdrawal (Briery & Rabian, 1999). Summer camps address these concerns by focusing on maintaining normalcy and instilling hope for the child who is critically ill and their siblings (Briery & Rabian, 1999). Camps throughout the country vary in their overall philosophical standing, but promoting a positive adaptation to illness is a common goal within the pediatric camp community. Within the past 15 years, much has been learned about the benefits of therapeutic camping for physically ill children, adolescents, and their families; in fact, over 80 camp facilities in the United States have been built specifically for children with chronic and severe illnesses.

Camp For All provides an environment that facilitates efficacy in peer relationships, and an atmosphere that is caring and hopeful. Established as a nonprofit organization in 1993, the site is located on a 206-acre property in Burton, Texas, an 80-mile distance from Houston. All facilities are wheelchair accessible and barrier-free, so all campers are able to participate in a curriculum that aims at providing opportunities to gain self-esteem and independence while having fun, learning new skills, and bonding with others who share their challenges.

During the week that this intervention was conducted at Camp For All, two groups were in attendance. Camp For All hosts the hematology/oncology departments from the Children’s Hospital at Scott and White in Temple, Texas (called Camp Dreamcatcher) and the University of Texas Medical Branch Children’s Hospital in Galveston, Texas (called Rainbow Connection). The two different groups represent two diverse cultures that merge while at Camp For All and the discrepancies between the groups will be addressed further as results of data collection paint a better picture of the differences.

**Zora Camp4All**

Midway through the week, the campers were introduced to the virtual Zora Camp4All through computers at the campsite. Campers were given a virtual tour and were shown the technical aspects involved in operating the program.

The Zora platform allows for the development of virtual worlds that are tailored toward multiple research venues, including hospitals (Bers et al., 2007; Bers et al, 2010). Zora is a multi-user graphical environment developed to provide opportunities for participants to construct and explore a virtual camp. Multiple users can interact within Zora through real-time chat and interactive avatars that represent each participant. Within the world, they can build objects, characters, and buildings to develop their virtual space. For example, campers were able to construct their personal cabin and decorate it with furniture and pictures from their week at camp.

The program was designed based on Bers’ positive technological development framework and provides technological features that allow adolescents to explore issues of identity while playing an active role in learning by creating virtual objects to share their stories (Bers, 2006; Bers et al., 2007). While the campers are engaged in constructing virtual representations of their week, they are also gaining technological skills to aid in their development and boost their sense of confidence and competence in the technological domain.

Before the campers’ arrival at Camp For All in June of 2009, the virtual camp was designed and main elements of the campsite were constructed (Figures 1, 2, 3). The campers built the remainder of the virtual space. The figures convey the virtual space, located at the center of the screen, and the real-time chat box, located at the bottom of the screen. Additionally,
the welcome page on the right side of the screen allows campers to construct objects and send messages to other users.

In addition to maintaining connections established at camp, the virtual world was developed to include activities intended to promote hopefulness, social connectedness, and positive technological development within the group of campers. The Zora Camp4All curriculum enhances hope through the use of specific strategies, delivered during six sequential sessions, using a small group interactive format. The curriculum was based on the Hope Process Framework by Ferran et al. (1992). Herth (2001) utilized the Hope Process Framework when designing the intervention titled Hope Intervention Program (HIP), planned to promote hopefulness in adults with a recurrence of cancer. Herth’s framework was focused on adults and did not include adolescents; thus, the Adolescents Self-Sustaining Model created by Hinds and Martin (1988) served as an additional theoretical base for the Zora Camp4All curriculum. In addition to synthesizing these two formats, curriculum goals that addressed social connectedness and positive technological development were also included. The virtual experience began when the campers returned to their homes after camp.

**METHOD**

In order to examine whether the program sustained hopefulness, a mixed methodology was chosen. The intent in using this design was to bring together the “differing strengths and non-overlapping weaknesses of quantitative methods (large sample size, trends, generalization) with those of qualitative methods (small N, details, in depth)” (Creswell, 2007, p.63). Specifically, this research employed the validating quantitative model of the triangulation design as cited by Creswell. The model explains that while both quantitative and qualitative data are collected simultaneously and analyzed separately, the results of the qualitative data are used to interpret the quantitative results.

**SAMPLE**

In order to participate in the study, campers had to fall in the 13-17 age range and receive permission from their camp director. Of the 120 camp attendees, 45 were eligible for inclusion in the study and 40 assented, resulting in a participation rate of 89%. Forty campers between the ages of 13 and 17 enrolled in the project at Camp For All, 22 from Children’s Hospital at Scott and White (Temple, Texas) and 18 from University of Texas Medial Branch Children’s Hospital (Galveston, Texas) (Table 1).

As Table 2 describes, the diagnosis distribution within the week was diverse. The large range within the table demonstrates the myriad of concerns that are utilized throughout the week; additionally, the campers are each at varying stages of their illness experience. For example, of the 16 campers who have experienced cancer, 2 were currently within treatment protocol, 14 others were off treatment, and 2 of the campers had experienced recurrence.

**DATA COLLECTION SEQUENCE**

Data collection sequence followed three phases. Phase 1 included baseline data collection of the hopefulness scale, a code of conduct, the consent and assent forms, and a demographic form. Phase 2 began as camp ended (after campers had been introduced to the technology but before curriculum implementation) and included the mid-point measurements of the hopefulness scale along with the mid-point semi-structured interview. Phase 3 concluded the project after the six weeks of curriculum with exit scales and an exit interview (Table 3).

**QUANTITATIVE TOOL**

The Hinds’ Hopefulness Scale for Adolescents was used to address the study’s first research goal, that the program, Zora Camp4All, sustains the campers’ hopefulness after their week at camp. The HSA contains a 24-item 6-point Likert scale designed to measure the degree of positive future orientation that an adolescent feels at the time of the measurement. This scale was chosen because it had been tested by Hinds and colleagues in diverse samples of adolescents, including those who are well, those who are

**Table 1: Hospital-Group Demographic Distribution**

<table>
<thead>
<tr>
<th></th>
<th>Camp Dreamcatcher n=22</th>
<th>Rainbow Connection n=18</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean Age</strong></td>
<td>14.6</td>
<td>15.4</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td>Rural- area around Temple, TX</td>
<td>Urban- area around Houston, TX</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>13 Females, 9 Males</td>
<td>10 Females, 8 Males</td>
</tr>
<tr>
<td><strong>Diagnosis Distribution</strong></td>
<td>9 siblings 3 blood disorder 10 cancer</td>
<td>9 siblings 3 blood disorder 6 cancer</td>
</tr>
<tr>
<td><strong>Ethnicity Distribution</strong></td>
<td>16 European American 4 African American 2 Hispanic American</td>
<td>10 Hispanic American 6 African American 2 European American</td>
</tr>
</tbody>
</table>
in residential treatment programs, and those experiencing cancer (Hinds et al., 1999; Hinds et al., 2000). The internal consistency estimates have ranged from .82 to .93, indicating moderately strong reliability (Hinds et al., 2000).

**Qualitative Tools**

Semi-structured personal interviews were conducted both at camp and upon returning home. The interviews contained five items addressing the youth’s attitude toward hope, five items addressing the youth’s attitude toward social connectedness, and five items addressing the youth’s attitude toward technology. Interviews were audio recorded and transcribed verbatim immediately after. Exit interviews were conducted by telephone as Berg (2007) explains that telephone interviews are “quite productive when [ . . . ] the researcher has already conducted face-to-face interviews or [ . . . ] developed a rapport during fieldwork” (p. 108). The interviews were recorded and transcribed verbatim. Transcripts were coded to identify recurrent themes.

All activity within the virtual world was logged in order to maintain records of what was built and to ensure safety. An online log provided opportunities for both qualitative (activities and coding of 3D creations) and quantitative data (e.g. log-on frequency and number of objects created). Logs were parsed to assess the number of objects, characters, and virtual spaces created as well as the number of on-line interactions that occurred during the study. The observations of logs and objects aid in understanding how Zora Camp4All sustains hopefulness.

**Data Analysis**

The HSA was measured independently for differences across data collection phases employing the Wilcoxon rank-sum test, used instead of Student’s t-test because normal distribution could not be assumed. According to Hinds & Gattuso (1991), the Hinds’ Hopefulness Scale for Adolescents can be completed in 4-9 minutes and scores can range from 6-144, with higher scores indicating higher levels of hopefulness.

All the results of this scale were analyzed for relationships with demographic variables such as diagnosis, as well as Zora Camp4All log data, including number of log-ins and number of curriculum objectives completed.

All qualitative data including interviews and logs was analyzed using an ethnographic approach aimed at gathering a rich set of data to construct an understanding of how Zora Camp4All assimilated into the pediatric camping community. The logs of on-line interaction as well as the interviews were coded for recurrent themes, including those that address hopefulness and the camper’s attitude toward the program. This process employed Miles and Huberman’s (2001) method of using charts and matrices for within-case and across-case analysis. The final system of charted codes was used to expand upon and embellish the quantitative data.

**Results**

The results from this study are presented in two sections. The first section addresses the impact that the pediatric camping experience had on the adolescents’ hopefulness. The second section describes the effect that the virtual camp, Zora Camp4All, had on the campers once they returned home.

**Hopefulness After Camp For All**

The baseline hopefulness scores within the participating campers indicate that the group, as a whole, came to camp with a high average level of hopefulness. Table 4 depicts the varying scores of hopefulness within the group. Those campers with illnesses came into the camp experience with higher hopefulness mean scores than the siblings. This is consistent with Cantrell and Lupinacci’s findings (2004) that adolescents who were ill had a significantly higher mean hopefulness score than healthy adolescents. Additionally, those who were new to Camp For All had a higher mean than those who had been to camp in the past.

As Table 4 describes, the mean scores of hopefulness increase within each of the groups. Despite this increase, there is a large gap in scores between the two different hospitals. Camp Dreamcatcher, the group from the Children’s Hospital at Scott and White in Temple, Texas, demonstrated a much higher mean upon entrance into camp than the other hospital. Rainbow Connection from the University of Texas Medical Branch in

**Table 2. Diagnosis Distribution**

<table>
<thead>
<tr>
<th>Category</th>
<th>Diagnosis</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oncology</td>
<td>Stomach cancer</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td>(n=16)</td>
<td>ALL</td>
<td>7 (17.5%)</td>
</tr>
<tr>
<td></td>
<td>Testicular cancer</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td></td>
<td>Langerhans cell histiocytosis</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td></td>
<td>Osteosarcoma</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td></td>
<td>Brain tumor</td>
<td>2 (5%)</td>
</tr>
<tr>
<td></td>
<td>Liver tumor</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td></td>
<td>Hodgkin’s lymphoma</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td></td>
<td>Burkitt’s lymphoma</td>
<td>1 (2.5%)</td>
</tr>
<tr>
<td>Hematology</td>
<td>Hemophilia</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>(n=6)</td>
<td>Sickle cell disease</td>
<td>4 (10%)</td>
</tr>
<tr>
<td>Sibling</td>
<td>No diagnosis</td>
<td>16 (40%)</td>
</tr>
<tr>
<td>(n=18)</td>
<td>Asthma</td>
<td>2 (5%)</td>
</tr>
</tbody>
</table>

**Table 3. Data Collection Timeline**

<table>
<thead>
<tr>
<th>Measurements</th>
<th>6/30 Phase 1</th>
<th>6/31-7/3 Phase 2</th>
<th>7/3 Phase 2</th>
<th>7/4-10/1</th>
<th>10/1 Phase 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code of Conduct</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assent</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demographics</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hopefulness Scale for Adolescents</td>
<td>X</td>
<td>Week at Camp</td>
<td>X</td>
<td>Curriculum from Home</td>
<td>X</td>
</tr>
<tr>
<td>Interview</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Zora Camp4All logs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

continued on Focus page 6
Galveston, Texas, had a mean that was 17.23 points lower than Camp Dreamcatcher; the large standard deviation for Rainbow Connection depicts the handful of scores within the group that act as outliers. Three individuals from Rainbow Connection have scores below 70 points, the clinical level of hopelessness (Hinds et al., 2000). Rainbow Connection sees mostly minority families from lower SES neighborhoods. Unfortunately, most research on hopefulness and hopelessness in youth has been conducted on European American middle class families (Grant et al., 2003). A study by Landis et al. (2007) describes adolescent stress and hopelessness in urban settings; the study concludes that chronic, uncontrollable stressors (poverty, community violence) were more highly associated with hopelessness in the sample. Although the scope of this project does not allow for further investigation, this large discrepancy provides opportunities for future research as it presents implications for the development of interventions to host multiple chronic stressors, not only illness.

Though the gaps remain, the jump within averages suggests that the camp experience does have a positive impact on the campers’ sense of hopefulness. As Table 5 describes, the mean hopefulness increase was significantly greater than zero, providing evidence that the camp experience is effective in enhancing hopefulness. When interviewed, the campers explained the various aspects of camp that they felt contributed to feeling hopeful. As Table 6 describes, campers were split between the lasting impact of both socialization and activities. This insight informs future research that the combination of both could lead to greater participation within interventions meant to mirror the camp experience.

### Hopefulness After Zora Camp4All

This section addresses the research question: Does Zora Camp4All help to sustain the campers’ sense of hopefulness after their week of camp? While the data suggests that camp does have a positive impact on the adolescents’ sense of hopefulness, the Zora Camp4All extension of the intervention attempts to produce similar results.

Two groups arose during the implementation of the 6-week camp from home. The curriculum cohort (n=10) includes campers who consistently participated in the objectives of the facilitated activities. The non-curriculum cohort (n=30) includes campers who chose to use Zora Camp4All as a vehicle for social connection and did not participate in the curriculum. Using these natural comparison groups, this section will examine the results of the two groups.

As Table 7 conveys, not only was hopefulness maintained, but for some populations, the mean hopefulness score increased once again. The table describes that a decrease in hopefulness was observed in two samples, the non-curriculum cohort and the entire Camp Dreamcatcher group. When looking closely at the results of the two cohorts, it is important to note that the curriculum cohort had a high hopefulness mean at the beginning of the project. This distinction indicates that the program might have been more appealing to individuals who already had a foundation of hopeful thinking patterns. Despite this, the difference within the curriculum cohort between Time-2 and Time-3 still suggests a positive impact on the campers’ hopefulness scores.

Table 8 illustrates that the mean hopefulness increase for all campers is not significantly greater than zero, which does not support the hypothesis that the Zora Camp4All program enhanced hopefulness within the entire group. The mean hopefulness increase in the non-curriculum cohort is also not significantly greater than zero. The curriculum cohort also demonstrated no statistical significance as the mean hopefulness increase in the group is not

---

### Table 4. HSA Scores after Camp4All

<table>
<thead>
<tr>
<th>Sample</th>
<th>N</th>
<th>Mean T-1 (SD)</th>
<th>Mean T-2 (SD)</th>
<th>∆</th>
</tr>
</thead>
<tbody>
<tr>
<td>Campers</td>
<td>40</td>
<td>94.65 (15.98)</td>
<td>99.38 (16.07)</td>
<td>4.7</td>
</tr>
<tr>
<td>Campers with an Illness</td>
<td>22</td>
<td>96.04 (14.73)</td>
<td>99.54 (16.32)</td>
<td>3.5</td>
</tr>
<tr>
<td>Campers who are Well-Siblings</td>
<td>18</td>
<td>92.56 (17.99)</td>
<td>99.13 (16.20)</td>
<td>6.6</td>
</tr>
<tr>
<td>Camp Dreamcatcher</td>
<td>22</td>
<td>101.54 (9.86)</td>
<td>105.54 (11.84)</td>
<td>4.0</td>
</tr>
<tr>
<td>Camp Rainbow Connection</td>
<td>18</td>
<td>84.31 (18.03)</td>
<td>90.13 (17.44)</td>
<td>5.8</td>
</tr>
<tr>
<td>Returning Campers</td>
<td>32</td>
<td>93.37 (16.71)</td>
<td>98.80 (16.53)</td>
<td>5.4</td>
</tr>
<tr>
<td>First Year Campers</td>
<td>8</td>
<td>101.25 (11.97)</td>
<td>104.38 (11.20)</td>
<td>3.1</td>
</tr>
</tbody>
</table>

### Table 5. HSA Score Changes after Camp4All

<table>
<thead>
<tr>
<th>Sample</th>
<th>Mean ∆</th>
<th>SD</th>
<th>t-test</th>
<th>P value</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Campers (n=40)</td>
<td>4.73</td>
<td>5.31</td>
<td>5.63</td>
<td>&lt;.0001</td>
<td>3.03-6.42</td>
</tr>
</tbody>
</table>

### Table 6. Aspects of Camp that Contribute to Hopefulness

<table>
<thead>
<tr>
<th>Sample</th>
<th>Coding Category</th>
<th>Codes</th>
<th>Frequency</th>
<th>Illustrative Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>All campers (n=40)</td>
<td>Socialization</td>
<td>Positivity</td>
<td>6/40</td>
<td>We encourage each other all the time like if someone needs help swimming then I encourage them and if someone needs help with cancer I encourage them.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Friends</td>
<td>9/40</td>
<td>I like the people in my cabin and they are all pretty cool and they make me feel hope to be here.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shared Illness</td>
<td>7/40</td>
<td>Just seeing how everyone is here and doing well enough to come to camp is hopeful.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Recreation</td>
<td>7/40</td>
<td>You are challenged here and you do things that I never thought I'd be able to do and that makes me feel like I could do anything.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Activities</td>
<td>11/40</td>
<td>Well there's the rock climbing and I love swimming and I like horseback riding. So [camp] lets you do lots of fun things.</td>
</tr>
</tbody>
</table>
significantly greater than zero. Thus, it cannot be suggested that Zora Camp4All promotes hopefulness. Despite this, the hopefulness scores were sustained and the three-week drop that was cited by Hinds (1988) was not experienced. This suggests that Zora Camp4All might have a hand in continuing the same hopeful atmosphere witnessed at Camp For All; although further investigation needs to confirm this finding.

Understanding that many factors contribute to feeling hopeful, data was analyzed for correlations between change in hopefulness and activities within Zora Camp4All. As Table 9 describes, the data could not confirm that the chosen elements of Zora Camp4All contributed to the change in hopefulness scores. The most noteworthy correlation was between the number of log-ins within the curriculum cohort and the increase in hopefulness; nevertheless, it did not reach statistical significance. However, given the small N, it would be unlikely to find statistical significance. Additionally, the scope of this project did not allow for testing of further variables included within the Zora Camp4All virtual community.

Both Phase 2 and Phase 3 interviews were coded to derive an understanding of the campers’ opinions on the impact of Zora Camp4All on their hopefulness. When asked specifically about the programs’ elements that contribute to hopefulness, the campers indicated a mix between maintaining connections, telling stories, and participating in activities (Table 10). During the coding process, it was noted that the curriculum cohort identified telling stories to be the greatest factor within Zora Camp4All contributing to hopefulness. Alternately, the non-curriculum cohort who used Zora Camp4All as a vehicle for staying in touch indicated that maintaining connections was the greatest contributing factor.

This segmentation within the results indicates that the curriculum encompassed in Zora Camp4All may be more appealing to individuals who value the story-telling aspect of the program. Alternately, those campers whose main priority is maintaining connections may be less inclined to participate fully in the curriculum activities. For example, the participant who logged-in most frequently yet never participated in curriculum or built objects, indicated in his interview the following:

I made lots of friends this week and I think Zora will be a way to you know, keep up with them because I don’t have like MySpace or anything so this will be good.

**CONCLUSIONS**

This pilot study indicates that the pediatric camping experience contributes to enhanced hopefulness for adolescents with chronic illnesses and their siblings. Likewise, the mean differences after using the virtual camp, Zora Camp4All, indicate that the hopefulness gained at camp was sustained continued on Focus page 8
after six weeks of being home. However, it cannot be confirmed that the tested elements of Zora Camp4All were contributing to a sustained sense of hopefulness. Due to the small N, correlations could not be found within the data indicating a connection between the tested elements of Zora Camp4All use and changes in hopefulness; additionally, the change in hopefulness after using Zora Camp4All was not statistically significant. Further investigations should be completed to confirm Zora Camp4All’s involvement in the sustainability.

This research does clarify that there are different patterns of use based on different developmental needs. For example, those individuals who wish to use Zora Camp4All to maintain connections may be less inclined to participate in the on-line curriculum. Other elements within Zora Camp4All, such as chatting, could contribute to the campers’ positive outlooks on the future. This research suggests that interventions should employ not only virtual support groups and educational curriculum but also time and mechanisms for socialization.

Finally, this pilot study highlights elements that are present in current research in the field. The discrepancy between hospital groups confirms that additional chronic stressors such as low-income urban environments must be taken into consideration when developing an intervention that hosts diverse demographics. Secondly, the gap between those campers who are ill and their siblings verifies that the sibling experience is an arena for future research and intervention implementation.

Acknowledgements

We thank Clement Chau, Laura Beals and Keiko Satoh from the DevTech research group at Tufts University as well as Kurt Podeszwa and the staff at Camp For All. We also thank the National Science Foundation for support of this research through an NSF Career grant # IIS-0447166 and the Deborah Munroe Noonan Memorial Research Fund. Any opinions, findings, and conclusions or recommendations expressed in this article are those of the authors and do not necessarily reflect the views of the National Science Foundation.

References


Parental Presence for Anesthesia Induction: Is It Best Practice?

Continued from page 2

In this review, limitations in the studies were evident. As the authors noted, many studies did not have enough power on which to base their results. Randomization was ineffective in many studies, which allows for the possibility of bias.

Parent anxiety was significantly less in one study for the parental presence plus midazolam group, while these same two factors reduce child anxiety in another study. Finally, three studies illustrated no significant differences between groups. When considering the evidence from all studies, the majority of studies showed no differences in anxiety between parental presence and no parental presence.

In this review, limitations in the studies were evident. As the authors noted, many studies did not have enough power on which to base their results. Randomization was ineffective in many studies, which allows for the possibility of bias. Nearly half were conducted at the same hospital, all of which had the same principal investigator, potentially skewing the evidence. Additionally, some participants and researchers overlapped amongst these studies. Using a more robust, meta-analysis evaluation was not feasible due to multiple types of anxiety measures and different points in time when anxiety was assessed across studies. Although this subject matter does not allow for a double-blind study design, the lack of double blindness increased the possibility of bias in the study results. Finally, the evidence scale used by the authors to evaluate these studies was not identified; therefore, the authors’ ratings of the studies cannot be evaluated.

Further research may enhance knowledge about the factors that affect anxiety during induction.

continued on page 8

H is for Healthcare Educators

continued from page 1

Inpatient settings. The specialists have adapted the materials for individual children and facilitated discussion on key asthma concepts. Online resources were provided which could be utilized for reinforcement once the child was discharged home.

The integration of child life specialists into healthcare education is not a new concept, but it is an important one that has not yet fully gained widespread acceptance. Child life specialists have specialized training in child development and communication techniques intended to engage and calm children, even in stressful situations. The American Academy of Pediatrics supports child life services as they focus on each child’s strengths to open the lines of communication and present information related to each child’s medical concerns (American Academy of Pediatrics Committee on Hospital Care, 2006).

In this project the child life team made three major contributions: (1) they helped children feel safe and more relaxed in an unfamiliar and potentially frightening situation, (2) they presented essential asthma information in a concise, easy to understand manner, and (3) they encouraged more effective patient communication with physicians and other healthcare providers. It is our belief that, through this effort of providing individualized patient support and education, we can enable the child to obtain a sense of control over their diagnosis. We hope that this will empower children with asthma and their families with a greater comfort level, which will encourage communication with their healthcare providers regarding their asthma management plan, therefore preventing additional ED or hospital visits in the future.

Our project was approved by the Institutional Review Board of Winthrop University Hospital. Participants were recruited from a population of children ages 6 to 18 years of age who were admitted to either our emergency department or inpatient service with asthma symptoms. The pilot group consisted of 29 children who received the intervention and who will be followed for one year. Initial analysis shows that 57% of subjects younger than 12 years and 85% of those 12 years and older had disease symptoms which were not controlled when assessed by the standardized Asthma Control Test. In all five subjects who have completed the 6-month follow up questionnaire, there was an improvement in the score.

Follow-up data will continue to be collected until participants have completed the one year post-encounter period. This pilot study is an encouraging experience supporting the benefits of incorporating child life specialists into the team of healthcare educators.

Reference
Parental Presence

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anesthesia induction and the effectiveness of parental presence. Investigation of factors such as parental behavior during induction, and the interplay between parent and child anxiety during induction, may clarify the conditions under which parental presence is beneficial. Lastly, a study amalgamating preoperative teaching programs and parental presence would be enlightening. The combination may decrease parent and child anxiety and enhance parents’ understanding of their roles when supporting their children through induction. Thus, coupling preparation and parental presence may result in more positive outcomes.

According to this review, the evidence does not currently support parental presence as an intervention in clinical practice to decrease anxiety during induction. The results, however, do show that parental presence is not detrimental in most situations and may help in some. For example, encouraging calm parents to escort anxious children, but discouraging anxious parents from accompanying calm children may be good choices to consider with appropriate assessments and preparation for the parents. Institutions’ decisions whether or not to offer parental presence reach beyond the effectiveness of the practice as an intervention to reduce anxiety. Parents may expect this option, and it can impact customer satisfaction and parental perception of a patient- and family-centered approach. Given that clinical practice balances and integrates the best available research evidence, clinical expertise, and the patient/ family values, healthcare professionals must consider parent and child preferences. Using the literature to develop guidelines to help staff and families determine which children and parents may benefit from parental presence, and which may not, may be appropriate.

Currently, many child life specialists routinely advocate for parental presence, believing it is effective in nearly all situations, but the literature suggests that separation may not intimidate some children, and children with anxious parents may cope more effectively without parental presence during induction. Child life specialists must have heightened awareness of cases where risks of elevated anxiety are possible and plan accordingly. Before advocating for parental presence, child life specialists must know what the evidence supports and integrate this knowledge into their assessments and practice.

November 2010 Exam Administration

CLC has recently partnered with a new test administration agency, Schroeder Measurement Technologies (SMT) and is pleased to announce that the November 2010 administration of the Child Life Professional Certification Exam will be offered via computer-based test administration (CBT) through SMT’s network of over 300 testing centers worldwide.

The application process has not changed. Applications for the fall exam are due by August 31, 2010 for anyone educated within the US or Canada, and by June 30, 2010 for those educated outside the US and Canada. Once an exam applicant has established eligibility, candidates will contact SMT to schedule their assessment at a convenient testing center between November 6th and November 19th.

The spring exam will continue to be offered in one location as a paper and pencil exam only at the site of the CLC Annual Conference on Professional Issues.

To offset the increased costs associated with offering CBT, candidates will pay an additional CBT fee of $75 for the fall exam administrations. For many candidates, the increase in exam locations will reduce the need for travel-related expenses, and for most, this will more than compensate for the additional fee.

More details will be forthcoming through the CLC website.

Recertification

For Certified Child Life Specialists whose certification cycle will expire on December 31, 2010, applications to recertify through Professional Development Hours were due on June 30, 2010. Applicants will be notified if more information is needed or if their application has been randomly selected for audit. After the applications have been reviewed and the audit is complete, applicants whose applications have been accepted will receive new certificates by mail late in the summer.

If you have not submitted an application to recertify by PDH and your 5-year certification cycle will expire on December 31, 2010, you can still recertify through PDHs. CLC will accept late submissions through the end of October. Candidates who apply for recertification between June 30th and October 31st are required to pay a $50 late fee and submit all supporting documentation (i.e. certificates of attendance) of the PDHs submitted. Late applications cannot be completed online.

Recertification candidates may also recertify by taking and passing the November 2010 Certification Exam.

Please contact Ame Enright, Manager of Certification, at AEnright@childlife.org with any certification related questions.
Bindy Sweett

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B. Models exemplary practice of child life through critical thinking, inquiry, evaluation, and a commitment to continuous improvement

Bindy worked with a medical student to develop a parent questionnaire to evaluate a family’s beliefs about access to play and the value of hospital play provided through the BCCH Child Life Department. Since then, the child life team has received requests from medical students to speak annually at their Pediatric Professional Days. Bindy also demonstrates modeling exemplary practice through her participation and thought-provoking comments on the CLC forum, which stimulates discussion and promotes reflective thinking.

C. Demonstrates advanced competencies and an ability to provide effective interventions in a variety of situations

Bindy demonstrates advanced competencies every day in her clinical work. Her beliefs in family-centered practice and collaboration guide her work. One example was when she worked with a family whose child had a cardiac arrest and needed emergency assistance. Bindy kept the family’s needs and wishes at the forefront of her interaction.

Her advanced competencies were also particularly evident when Bindy was supervising interns. Bindy was a mentor and coach to students, and under her supervision, many went on to become excellent clinicians.

D. Models child life practice and team behaviors that acknowledge and respect the diversity of patients/families and members of the healthcare team

Bindy completed thoughtful assessments that were the basis of her therapeutic interventions. These assessments always incorporated cultural and diversity issues.

For example, Bindy worked extensively with a family from a very small, northern First Nations community. To help combat the distance and separation they were experiencing being away from their large close-knit family, Bindy set up one of our very first video links. This was at a time when this type of technology was not prevalent; however Bindy was committed to supporting the family in the way that was most important to them.

E. Demonstrates strong professionalism and values driven interactions that include clear, caring-boundaried, and professional relationships with patients and families

Bindy has been a role model for others in maintaining professional boundaries, while still developing close, therapeutic relationships with patients and families. According to one family, whose child has a cardiac condition and with whom Bindy has worked extensively, “Bindy has been there for us throughout Johnny’s many stays at BCCH, whether it be open heart surgery, a heart cath, or just a patient visit since his birth 12 years ago… He has never been afraid of coming to BCCH no matter what has to be done.”

F. Exercises sensitivity to the individual patient’s/family’s circumstances and provides supporting and nurturing care

Bindy has worked with children and youth with cardiac conditions for much of her 22 year career. As such, she often works with highly anxious, complex patients and their families. There is seldom a time when a family who returns to the hospital, even for a short visit, does not stop by the child life office to look for Bindy – most times, it is to say a very heartfelt “thank you.”

G. Embraces and models the core concepts of family-centered care including information sharing to support patient/family participation, collaboration and involvement in their care

Bindy has been the recipient of two Family Centred-Care (FCC) Awards. These are awarded on the premise “that the best care for children happens when hospital staff and families work in partnership following the principles of FCC.” In one of Bindy’s nominations, the family stated, “She was there when Ricardo* had his pacemaker placed at 7 years of age. I was planning to go into the OR with him until he was put under but I was not sure they would allow this, so she was there as a backup at Ricardo’s request…Her sense of humour and ability to read families has made BCCH a fun place for Ricardo rather than the scary place so many children see.”

H. Participates in the development and incorporation of evidenced-based practice

In 2005 and 2006, Bindy was a CLC Board member (member-at-large) and served as the liaison for the Evidence-Based Practice (EBP) Committee. In this role, Bindy was instrumental in initiating a contract for the development of our current EBP documents. As a strong believer in EBP, Bindy incorporates this commitment into her day-to-day practice, ensuring that any information the department distributes, for example, our Student Internship Manual, is evidence-based and appropriately referenced.

I. Mentors new child life specialists and students in developing child life competencies and supporting the effective transition to professional practice

The first introduction many of our interns receive to the profession of child life is through the course Bindy teaches, Child Life Practice in Hospitals and Community Settings. Bindy provides “real life” child life training, using creative presentation skills to introduce the child life core competencies. As one of Bindy’s former students commented, “she leaves us mesmerized!” Bindy’s students maintain strong ties with her, often seeking professional advice on practice issues.

J. Actively participates as a member of the Child Life Council

Since becoming a member of CLC in 1988, Bindy has held the following positions: Certification Chair, Board Member-at-Large, Chair/Co-Chair of Professional Resources Committee, and Member of Education & Training Committee and Program Review Committee. Bindy has also presented at numerous CLC conferences, been a contributing author and/or reviewer of numerous CLC publications including the 2009 Focus article on Advocacy.

The words of these endorsers echo the sentiments of Bindy’s colleagues, students, patients, and families; they respect her as an exceptional child life specialist, educator, presenter, mentor, advocate, trainer, author, and facilitator. Bindy has demonstrated her dedication to the child life profession and is known for maintaining only the highest standard possible. CLC proudly awards Bindy Sweett, CCLS with the inaugural Mary Barkey Clinical Excellence Award.

*Patient name has been changed for confidentiality
Child Life During H1N1

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ensured props were cleaned between patients, and clowned outside of the windowed door of isolated patients.

Develop Resources

The Child Life Department worked with Nursing and Infection Prevention and Control to create new resources in response to the H1N1 outbreak. Together we developed recommendations for unsupervised ward playrooms and waiting rooms in Children’s Hospital. Child life specialists also developed a specific tips sheet for the Winnipeg Regional Health Authority to help children cope with getting an H1N1 immunization shot (Table A). Wherever we made a change in practice, we incorporated the change into our child life departmental documents.

Point of View from Children’s Hospital Administration

Susan Fogg, Program Director of Child Health Public Services, acknowledged the contribution that child life made during the crisis: “Our experience with the H1N1 pandemic was intense. There were many unknowns. Throughout June and July 2009 our Children’s Hospital was challenged to meet the needs of our population and we were glad to see phase one subside. All of our staff went above and beyond the call of duty to care for the many infants, children and youth who experienced severe H1N1 illness, and all those who presented to our Emergency Department for assessment and care. On behalf of the Child Health Program, I would like to thank our child life specialists for their unique contribution to our community during this worldwide event. They are highly valued members of our health care team.”

Summary

Overall, the experience with H1N1 challenged us all. We learned that we could improve our infection control practices, and that some were no longer acceptable. We explored and developed alternative modes of practice that would still meet our goals of providing for children and families. We partnered with the healthcare team to ensure we were supporting each other and continuing to meet the needs of children and families (for example, we couldn’t just ask a waiting room to remove all their toys without providing alternatives such as giveaways, movies to watch, and storytimes). We also learned that families were willing to support measures that increased their safety, and that these measures increased their confidence in us. We learned that child life could work collaboratively with other disciplines to address a pandemic in a timely, flexible and adaptive manner. The H1N1 pandemic taught us all a lot, including that pulling together as a team works!

Table A: Tip sheet created for the Winnipeg Regional Health Authority, Canada during the H1N1 outbreak in Spring 2009

Going for a needle may be frightening or difficult for your child. Here are some tips that you can use to help your child in this situation.

- Tell your child about the procedure ahead of time, depending on your child and their age. Some suggestions are:
  - Toddlers: at the time of the procedure
  - Preschoolers: a few hours before the procedure
  - School-age: 1 – 3 days before the procedure
  - Adolescents: 1 – 2 weeks before the procedure, or as soon as you find out about it

- Prepare yourself. If you feel calm and relaxed, your child will sense this and act the same way.
- Take a familiar toy, teddy bear or blanket with your child - it provides comfort for your child.
- Reassure your child. Make sure your child knows going for a needle is not a punishment and that they did not do anything wrong.
- Tell the child they are getting the medicine to keep them healthy and safe, and it must go into their arm because it is not the kind you can eat or drink.
- Be honest with your child that it may hurt.
- Use gentle and simple language that your child will understand without being scary. For example, “You may feel a quick pinch when they put the medicine in your arm. Afterwards, your arm may feel a little tired or sore.”
- If you are taking more than one child, have the child who is calmer go first as they will set example for the younger or more fearful child.

During the procedure:

- During the procedure, try to find positions of comfort and support for your child to help them stay still, such as the “hug hold” – child sitting on your lap facing you or sideways while you restrain the child with a comforting hug.
- When possible, give your child choices, e.g. choosing which arm to have the needle in. Having some control helps. Give your child a time limit during which to make that choice. Other choice examples are: to look or look away; to sing a song or count while it is happening; to choose a particular bandage design/colour afterwards (if offered), which candy or sticker reward (if offered) they would like.
- Give your child the job of holding still during the procedure. If they have brought a stuffed animal, they can hold still with them.
- Offer distraction during the procedure, such as singing a song, blowing up an imaginary balloon, counting till it’s over, etc. You could offer sensory distraction by rubbing the other arm during the procedure. The child can also “blow the pain away” after the procedure.

Always:

- Listen to your child’s concerns. It is okay for your child to ask questions, cry or talk about his/her feelings. Crying helps get rid of tension, anger and hurt. Crying is healthy.
- Praise your child!
- Some distractions waiting rooms could provide while the child is waiting:
  - Television – movies or cartoons
  - Colouring sheets, mazes and individual crayons (to keep due to infection control)
  - Word searches for older children – can download from sites such as
    http://www.abcteach.com/directory/fun_activities/word_searches/

*Please see the list of suggested coping techniques for different ages on the reverse

Child Life Department, Children’s Hospital, Health Sciences Centre, Winnipeg
Have You logged on to CLC Community?

CLC Launched CLC Community, the new professional networking site, in June, shortly before the Annual Conference in Phoenix. During the opening session at conference, then-CLC president Ellen Good asked for a show of hands of how many people had already logged on to view the new site. A remarkable number of attendees raised their hands, demonstrating just how popular CLC Community is becoming! Nearly 2,000 CLC members have already checked out the new site; if you are not among these, we encourage you to log in and experience for yourself what all the buzz is about! Below are some of the new capabilities of CLC Community, and how it can benefit you as a CLC member:

Forums—while the forums are not new, improved system capabilities make it easier to manage your own subscriptions, set vacation settings, and attach files to your messages. An enhanced search feature allows you to quickly access and review older discussion threads on popular topics that frequently appear on the Forum.

Blogs—a new way for members to communicate! All members now have the ability to create their own blog, and share their thoughts and opinions based on their own professional or personal experiences. Many members have already started a blog, and several have already posted several installments. Be sure to check the blog section so you don’t miss out!

File Sharing—this tool empowers all members to contribute to the collective knowledge of the child life community, by allowing them to store and share valuable resources in an online library. A robust search function means that all uploaded documents are easily accessible to other members looking for information on a particular topic. Examples of files that have already been uploaded include a sample VCUG prep book, injection tips for caregivers, a Spanish patient checklist, and more. We encourage you to check in often and look for updates from your colleagues, then consider contributing a file or two yourself!

Member Profiles—every member has the chance to create their own My Page, with a profile picture, contact information, professional interests, a biography, and more. You can also add links to outside content such as your LinkedIn or Facebook profiles, your Twitter page, blogs from sites like Wordpress, or photo slideshows from Flickr and Picasa, just to name a few.

We hope that this is a member resource that will encourage our child life community to collaborate on projects, share resources, and communicate better with each other! If you have any questions about how to navigate CLC Community, please email: communityadmin@childlife.org.

School Reentry

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social worker to compile information about each school-age patient’s reason for hospitalization or diagnosis, goals achieved in therapies, and possible challenges upon return to school. Each therapist on the team contributes data about the patient’s progress and relevant school recommendations by writing notes in a shared binder that I created as a unified gathering place for team members’ information. Using this valuable resource of combined reports from all of my team members, I am able to create a developmentally appropriate PowerPoint presentation geared toward the patient’s classmates. In addition to text, I add digital images to give a more visual explanation for the students and to provide a clearer view of the patient’s hospital experience. If the patient’s address falls within our approved zip code range, our school teacher, social worker, and I make a personal presentation to the classroom. If patients are willing and able, they may also accompany us to their schools.

Although our school reentry process at St. Louis Children’s Hospital is certainly not flawless, it has allowed us the chance to further explore the needs of our Neuro Rehab patients and their families. Developing a successful school reentry program, particularly for patients who have experienced significant physical, cognitive, and social changes, is essential to improve family-centered care in pediatric hospitals. As child life specialists, we have the tools and skills to assist our patients in transitioning back into the school environment. Our knowledge of developmentally appropriate preparation and education can help us create an engaging and understandable presentation. However, it is the collaboration with other disciplines and implementation of all possible hospital resources that allow us to achieve significant success in the often-neglected field of school reentry.

REFERENCES


CLC Calendar

**JULY**
- 15  Deadline for Bulletin and Focus articles for Fall 10 issue
- 30  Deadline for abstract proposals for the 29th Annual Conference on Professional Issues

**AUGUST**
- 31  Deadline for applications for the November administration of the Child Life Professional Certification Exam for those educated within the U.S. or Canada

**SEPTEMBER**
- 17-19  CLC Conference Planning Meeting

**OCTOBER**
- 15  Deadline for written requests to withdraw from November Administration of the Child Life Professional Certification Exam

**NOVEMBER**
- 6-19  Child Life Professional Certification Exam Administration testing window
- 12-13  CLC Executive Board of Directors Meeting

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**VISIT THE CHILD LIFE MARKETPLACE**

If you haven't had the opportunity to visit the Child Life Marketplace, you could be missing out! The directory provides convenient access to contact information from a growing number of organizations that work with the child life community, and some vendors are also offering discounts and special offers exclusive to CLC members. If you have worked with one of the businesses or nonprofit organizations listed in the Marketplace, consider sharing your experiences with your colleagues by rating and commenting on a listing. Be sure to visit regularly to check out what's new on the site!